# AIDS and People with Severe Mental Illness

A Handbook for Mental Health Professionals

Cognitive-Behavioral Risk Reduction Groups
for Teaching Safer Sex

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There has been some concern that the cognitive and behavioral symptoms of mental illness may make intervention to encourage safer sex practices particularly problematic.[1] Sex is often a difficult topic to discuss, and some staff fear that raising the topic with people with severe mental illness may encourage sexual disinhibition. (A similar argument is invoked in opposing sex education in schools.) But the recognition that this population may be at increased risk for HIV infection makes supplying risk reduction education an ethical imperative.

In reviewing existing HIV prevention models, we found several successful interventions for other populations-among them gay men and runaway adolescents[2]—based on cognitive-behavioral skills training. These were not concrete or repetitive enough for a mentally ill population. Other training programs had successfully increased knowledge about HIV and high-risk behavior among psychiatric patients.[3] But knowledge in itself does not change behavior, as was indicated by a study that found that 89% of patients who had been sexually active in the previous six months used condoms inconsistently or not at all, although 84% of them believed that using a condom during sex helps prevent AIDS.[4]

A cognitive-behavioral intervention would be most likely to help mentally ill patients concentrate on changing unsafe sexual behaviors. This kind of intervention focuses on overcoming resistances to behavior changes rooted in attitudes, beliefs, habits, and feelings while also ensuring that patients have ample information about HIV.

**Intervention**

An earlier study conducted by members of our research team demonstrated that during lengthy sexual history interviews with psychiatric inpatients and outpatients, none experienced aggravated symptoms or other negative consequences from talking about sex.[5] Some patients said they appreciated being asked about a "normal part of life" rather than their psychopathology. Consequently we felt comfortable in developing a clinical intervention using explicit sexual material. following implementation, conducted an informal evaluation.

The techniques used in the intervention are designed to confront unsafe sexual behaviors and the motivations for them. They are intentionally repetitive to ensure that learning and practice can be transferred to the patient's life outside the session. Changes in attitude often follow changes in behavior: we hoped that a person who learns to use condoms despite his dislike for them will eventually develop more positive attitudes toward using them.

Because patients must learn to negotiate safer sex behavior with their partners, avoiding high-risk behavior requires interpersonal skills and emotional awareness. Many patients need help in being assertive and refusing to participate in unsafe sexual practices. The topic of AIDS is depressing and frightening; patients must be made aware of the feelings the topic may elicit and

be able to recognize, label, and effectively handle their emotional responses.

The intervention consists of ten sessions. The sessions are designed so that they can be used alone, repeated as often as necessary, or run as a group of sessions. It is best to have two group leaders, so that one can direct the activities while the other monitors progress. offers feedback, and keeps the group focused on the current activity.

Successful intervention with mentally ill patients, as with all people, is complex and requires that help he offered in a supportive, nonjudgmental and positive environment. It is important to keep in mind the unique needs and stressors of individual patients. In the first session, introductions are made. ground rules are set, and a warm-up activity is introduced to increase comfort and communication between group members. Succeeding sessions begin with a warm-up and a review of the previous week's material. Each session also contains a section on goals for the future, to emphasize that success in fulfilling your goals will depend on staring healthy by practicing safer sex. Here is a description of each of the sessions.

Session 1: What is safe? Here participant's learn to become more comfortable using sexual words and learn more about safe versus unsafe sexual behaviors. A sexual knowledge test is given to establish levels of knowledge.

Session 2: Myths about AIDS and what I need to know. The session focuses on the transmission of HIV, concentrating on identifying common myths.

Session 3: How serious is the threat to me? Participants learn to perceive the threat of HIV and AIDS as real and to increase skills in screening sexual partner for HIV risk.

Session 4: How to use a condom and dental dam. This session, for both men and women, concerns the need to take responsibility for safer sex by properly using condoms or dental dams. Often there is anxiety about condom use, In this session, patients practice handling condoms1 playing with them to reduce anxiety and gaining skill in using them.

Session 5: High-risk situations. This session shows patients that they must become aware of the situations in which they find it difficult to employ safer sex strategies. By knowing their own high-risk situations, they can learn to cope n-idl them. Patients also need to be aware of positive reinforcements that encourage unsafe sex acts, such as rewards of money, cigarettes. or acceptance. They must realize when they are rationalizing unsafe behavior by telling themselves it is all right to engage in unsafe sex, and they must become aware of how self-destructive this is.

Session 6; Direct talk about sex and AIDS. In this session, participants are taught to handle interactions with others, both individually and in groups. The focus is on social skills, including self-confident communication in which requests and refusals are made in an assertive manner. These skills enhance participants' abilities to negotiate safer sex with partners. Patients also need to be aware of what is unsafe, abusive, or coercive behavior and how to

handle it.

Session 7: Coping with the pressure to use drugs and alcohol. The goal of this session is to help patients understand that inhibitions are lowered when they use drugs or alcohol and that they should practice safer sex even if they are high. Studies show that large numbers of people with severe mental illness at some time drink alcohol or use drugs, and many have documented substance abuse problems. Preaching is ineffective and should be avoided. Role plays are used to help patients determine how drugs and alcohol may alter their ability to practice safe sex. Patients who are known to have used substances in the past and are trying to remain drug free will need extra support in resisting peer pressure. Because people with severe mental illness can be isolated and have difficulty developing friendships, they may have difficulty establishing new peer groups in the face of continued pressure to use drugs.

Session 8: HIV and family planning. This session includes a discussion of strategies for HIV prevention and family planning. which are often connected. In addition, patients need to know facts about the relation between HIV status and childbearing in order to make responsible decisions.

Session 9: Should I be tested? Whether to undergo HIV antibody testing is a serious decision that should he made in the context of understanding the risks and benefits of having this information. This session assists patients in making informed choices.

Session 10: Understanding medication and its sexual side effects. Controlling psychiatric symptoms with appropriate medication will often strengthen patients' ability to make safer sex choices. Patients need to understand the importance of continuing their medication in order to be able to make safer sex decisions: understand that stopping medication can sometimes lead to hypersexuality and unsafe sex; and learn to be comfortable talking with staff about sexuality, medication, and specific sexual side effects associated with psychotropic medications.

**Training Providers**

We not only developed and ran this HIV risk reduction program, but we also received funding to teach other providers to do so. Our first attempt to train staff to run HIV risk reduction groups W8S at a large state psychiatric hospital in New York City. The initial group consisted of 40 mental health professionals. Many were dubious about the chances for success of intervention groups, believing that patients would not attend, would not participate if they did attend, or would attend and participate but experience an exacerbation of symptoms in the process, After several weeks of debating whether HIV prevention groups could he conducted with severely mentally ill people, we decided to run a trial group. Patient participation was good, and staff fears of disaster dissipated, but other problems arose. Our training assumed that staff had basic information about HIV and its transmission, but in fact the level of understanding among staff members was highly

variable. A more significant obstacle was the lack of training among mental health professionals in the area of sexuality and their discomfort in discussing sexual topics. Many clinicians felt uncomfortable with an interactive format and were particularly concerned about being group leaders for patients they had treated in other contexts, such as individual psychotherapy. Some leaders reported that they treated patients for years in individual therapy without ever bringing up sexual topics.

In our experience, people with mental illness are knowledgeable about HIV disease.[6] Psychiatric patients score as well on a standard AIDS knowledge questionnaire as many professionals in the field. But like all groups, psychiatric patients often believe in myths. These false beliefs need to be corrected in a way that does not demean the people who hold them. A patient who is actively psychotic may have misconceptions based on delusional material, and it is vital that the group handle these in a respectful manner while ,discouraging the delusional thought. For example, in a group conducted shortly after the release of the movie "Interview with the Vampire," a patient politely asked if there was a safe way for a vampire to suck blood. The group leader avoided a discussion of vampires and simply said that sucking blood under any circumstances was not a safe practice. She neither ignored the question, nor allowed the group to be sidetracked by an irrelevant discussion.Instead, she gave information without confronting the patient's delusion.

It is not unusual for a patient to try to open a debate about where AIDS started. We advise avoiding this discussion as it inevitably leads to a swamp of prejudice and misinformation.

**Key Elements in Conducting the Intervention**
**Awareness of Comfort Levels**

A "feeling thermometer" should be used regularly throughout the groups, so the group leaders continue to be sensitive to the level of anxiety that discussions elicit. This is a scale from one (totally calm) to ten (highly anxious). We pause periodically to ask participants to rate and report their comfort with the subject being discussed. We incorporate this feeling thermometer into both patient groups and staff training groups; in the latter instance, it is used to monitor staff anxiety with sensitive subjects.

**Condom Distribution**

Since many people with severe and persistent mental illness are indigent, a strategy for free distribution of condoms is vital to a successful HIV risk reduction program. This must include a means for patients to receive an adequate number of condoms without having to ask a staff member for them. This is not as simp!e as it sounds: many programs have limited funds to purchase condoms, and staff may be resistant to giving patients access to them. In past training sessions, some staff have made such statements as "they will just waste them and make water balloons out of them!”

Anonymous availability of condoms is crucial, because many patients feel ill at ease asking doctors, nurses, or other clinicians for them. Patients have reported that they perceive that staff have negative attitudes toward sex and

consequently toward condom use. Patients have also told us that staff are too busy with other duties to stop to give out condoms. Often group leaders themselves may become responsible for assuring that condoms are available and may have to overcome resistance from the administration of the institution to allocating funds for them.

If condoms are not available at a program, we suggest that the group leaders check into local health department programs or free condom programs sponsored by manufacturers. Running an HIV risk reduction group in a setting where condoms are not available will have limited value. The inability to distribute condoms has created serious and as yet unresolved problems in training staff at religious institutions where condom distribution is prohibited.

**Role Play**

Our experience has shown that role playing is essential in allowing participants an opportunity to practice being in difficult situations. It is important for the group leaders to be comfortable with this technique. Often. the group leaders can perform the first scene, then a leader can role play with a group member. Groups may also use role reversal (men playing women or patients playing doctors) to make the situation less threatening, In training sessions, many mental health professionals have expressed concern about participating in sexually explicit role plays in groups with patients they had treated. We recommend a commonsense approach. Leaders need only role play situations where they feel comfortable. If both a leader and co-leader are present, they can first role play with each other and then get patient volunteers to do a separate role play.

Role plays should be simple situations like those actually encountered in patients. There are two types of role plays: one in which both parts are scripted and the other in which one participant's reply is left open-ended. In each case, the scene is set beforehand by the leader, and patients are encouraged to be creative. The goal, however, should always remain clear: to encourage patients to practice safer sex. Here are two examples.

1. *Both roles are scripted,*
SCENE: Ann has just been discharged from a psychiatric hospital where she received HIV counseling. She's with her boyfriend Roberto, and they're both interested in having sex. Ann explains what she's learned at the hospital about the importance of using condoms.
Roberto: I'm not using a rubber.
Ann: Look, I've told you before that I don't want to take a chance on getting HIV. It's really important to me that you use one.
Roberto: I'm clean! Don't you trust me?
Ann: Please use the rubber.
Roberto: No way!
Ann: No way. then no sex. I like you. I want to have sex with you, but I'm more important than having sex. Let me know when you are ready to use one.

2. Only one role is scripted.

Scene: You go over to your good friend's to hang out. Your friend is smoking crack and is pretty high. He offers you some, but you resist smoking,
Friend: Take a smoke. I got plenty of it—good stuff. Come on, you'll love it.
REPLY:
Friend: It's not going to hurt you. Really! Are you my good friend or not? I'm telling you it's the best I've had in years.
REPLY:
Friend: Don't give me that shit! Wait till you see what else I got. Really hot porno pictures. They will really get you wet. I'm so horny. Please. You got to try this crack.
REPLY:
Friend: You're in such a bad mood. This stuff will help you, seriously.
REPLY:

**How to Start and Maintain a Group**

Leading groups such as those described above requires a basic knowledge edge of HIV and reasonable comfort with sexual issues, but not a high degree of technical or scientific expertise. Generally, paraprofessionals are perfectly capable of leading groups. All leaders should remember that when questions arise to which they have no answer, the best response is to say that you are not sure and that you will find out and report back in the next session,

Patients usually enjoy talking about sex, especially if the topic is presented in an engaging manner. Some clinicians, however, have expressed concerns about how to get patients to attend. In our experience such incentives as food, small prizes, and transportation money help induce patients to participate. If there are limited resources available, the leaders may supply candy, potato chips, Of pretzels at the first and last session.

The question of including sexually abstinent patients in these groups has been widely discussed. We recommend including them. First, patients abstinent today will nor necessarily he abstinent forever. Second, many patients have used what they learned in the group to talk to their friends and families, including their adolescent children, about HIV, birth control and the other topics. For example, in one group, an elderly patient took a large number of condoms and said with an embarrassed look that they were for her grandchildren. And finally, abstinence is a legitimate choice of life style, so abstinent members offer an approach that other group members could consider.

**Handling Problems in the Sessions**

In general. psychotic remarks, such as "The condoms are poisoned," should be ignored, Participants should he redirected toward appropriate behavior, and unrelated issues should be referred to the treatment team. Often patients become distracted or focus on the wrong topic. When this occurs we suggest:

1. Bringing the discussion back to the topic at hand: "Something I said must have gotten you off the topic. We were talking about ... "

2. Asking the person to focus on the session's topic.
3. Exploring discomfort. Try to find out what is bothering the person.

We do not encourage patients to reveal their HIV status in the groups, however, in many cases they choose to do this. If a program has a large enough number of patients who know they are HIV positive, it may be useful to separate them from the general population of patients and run a group specific to their concerns. In any case, it is very important for group leaders to allow 15 minutes at the end of each session for participants to discuss personal issues privately. Group leaders should he prepared with lists of local referral sources including testing sites.

**Use of Videos**

When a television set and a VCR are available, videos can be used to stimulate discussion. A number of helpful videos are listed at the end of the chapter. It is best to show five-to-ten-minute sections with immediate discussion afterwards. Before the session, group leaders should watch and carefully choose the segment, to make certain they are familiar with the content.
Videos should be appropriate for each group. Some videos may be too explicit for some populations. Factors that should be considered are age, cultural background, gender, and sexual orientation.

**Evaluating Effectiveness**

Using a knowledge questionnaire and several questions about sexual practices, we evaluated four groups of outpatients who attended the risk reduction intervention we've described here. Of the 45 participants, 26 completed the evaluation. Of this sample, half were men and half were women; 9 were 39 years old or younger white 17 were age 40 or older; 8 were white, 7 black, and 11 Latino; 20 had psychotic disorder (mostly schizophrenia), and 6 had an affective disorder.

Twenty-two responded correctly to at least nine of ten knowledge questions, 23 said they were more likely to use a condom during sex since attending the HIV risk reduction group, and 20 stated that since attending the group they were less likely to have sex with people they did not know. Three-quarters of parents reported that they were more likely to talk to their children about HIV-related issues, and in several cases they noted that this would be the first forthright discussion of these topics with their children.

Three-quarters of the group members thought the group was very important and should be continued at the clinic. The remaining members thought it was somewhat important and should be repeated occasionally. Group attendance was substantially higher than is usual for clinic groups. Staff reports indicate that further discussion of safer sex and HIV-related issues spilled over into other clinic groups and that condom requests throughout the clinic increased fourfold. In addition, informal discussions regarding the intervention were overheard among patients.

These observations suggest that risk reduction groups are well received and well tolerated and that patients express the intention to change their

behavior, although measuring if they actually do is a much more difficult task. Future research is needed to examine behavior changes as a result of these groups, especially changes in condom use.

Studies with other populations have indicated that those who participate in similar risk reduction groups practice safer sex while attending group sessions and continue to do so afterwards.[7] However, without the groups safe sex practices fall off after several weeks. Based on our experience, we recommend monthly follow-up groups for relapse prevention. Our conclusions are supported by a recent study demonstrating that cognitive-behavioral interventions with a group of severely mentally ill patients led to increased condom use at one-month post-intervention, but that the gains were beginning to fall off at the two-month follow-up.[8]

Like any behavioral changes, practicing safer sex requires consistent commitment and work. Changes will not be permanent if they are not regularly reinforced. This type of reinforcement becomes all the more urgent when working with an HIV-positive population.

We have co-led groups with, collectively, hundreds of people suffering severe mental illness and have found patients to be active participants in their own education. These groups are very popular, and patients regularly ask for more groups of this kind. In spite of some prior fears, we have seen neither an exacerbation of symptoms nor inappropriate behavior attributable to group participation. We believe HIV risk reduction and transmission groups are an essential part of the overall treatment for sexually active or drug-using people with mental illness. Certainly they must he a regular part of any program that treats dually diagnosed people with mental illness and substance disorders.

**Useful Videos**

A First Step. 1989. Length: 19 mins. An injection drug user and his girlfriend confront AIDS and drug use. New York State Department of Health, AIDS Institute, ESP Tower, Room 270, Albany, NY. 12237.

AIDS Is About Secrets. 1988. Length: 37 mins. For female partners of HIV positive drug users, HIV Center for Clinical and Behavioral Studies, 722 W. 168th St. New York, NY.10032.

AIDS Knowledge. 1989, Length: 60 mins. Clinicians and group members talk about AIDS-related issues. Young Adult Institute, 460 W. 34th St., New York, NY. 10001.

AIDS Not Us. 1989, Length: 35 mins. For inner-city adolescent males. HIV Center for Clinical and Behavioral Studies, 722 W. 168th St., New York, NY. 10032.

AIDS: Life Goes on Regardless. 1993. Length: 36 mins.A peer-education play for teaching HIV prevention techniques to people with disabilities. Young Adult Institute. 460 W. 34th St. New York, NY. 10001.

AIDS: Me and My Baby. 1990. Length: 22 mins. For HIV·infected mothers HIV Center for Clinical and Behavioral Studies, 722 W. 168th St., New York, NY. 10032.

AIDS: Teaching People with Disabilities to Better Protect Themselves, English and Spanish versions. 1988. Length: 17 mins. Explicit and simple description of HIV transmission and prevention. Young Adult Institute. 460 W. 34th St., New York, NY. 10001.

Facing AIDS. 1988. Length: 30 mins, A young man with AIDS answers questions about the disease. NewYork State Department of Health, AIDS Institute, ESP Tower, Room 270. Albany, NY, 12237.

Jugandose la vida: la razon por la cual los drogadictos deven informarse sobre el sida. In Spanish. 1990. Length: 15 mins. A drug user comes to terms with his drug habit after learning that his lover is pregnant. Includes a demonstration of cleaning needles with bleach. New York State Department of Health, AIDS Institute, ESP Tower, Room 270, Albany, NY. 12237.

Se Met Ko. In Creole with English subtitles. 1989. Length: 28 mins. A dramatization of a Haitian family dealing with AIDS. New York State Department of Health, AIDS Institute, ESP Tower, Room 270, Albany, NY. 12237.

Una cuestion de vida o muerte: una historia sobre el sida. In Spanish. 1988. Length: 20 mins. In soap opera format, the story of one family affected by AIDS. Includes discussion of transmission, casual Contact, and safer sex. New York State Department of Health, AIDS Institute, ESP Tower, Room 270, Albany, NY. 12237.

**Notes**

1. J, Kelly et al., "Psychological factors that predict AIDS high-risk and AIDS precautionary behavior," Journal of Consulting and Clinical Psychology 58 (1990). 117-20.
2. J. Kelly et al., "Behavioral intervention to reduce AIDS risk activities," Journal of Consulting and Clinical Psychology 57 (1989), 60-67; M. Rotheram-Borus et al., "Reducing HIV sexual risk behaviors among runaway adolescents," Journal of the American Medical Association 266 (1991): 1237-41.
3. B. Lauer-Listhaus, J. Watterson, "A psychoeducational group for HIV-positive patients on a psychiatric service," Hospital and Community Psychiatry 39 (1988): 776-77.
4. K. McKinnon et al., "The relationship between psychiatric symptoms, AIDS knowledge, and HIV risk behaviors among people with severe mental illness," manuscript under review.
5. Ibid.
6. Ibid.
7. M. Rotheram-Borus et al., 1991.
8. S. C. Kalichman et al., "Use of a brief behavioral skills intervention to prevent HIV infection among chronic mentally ill adults," Psychiatric Services 46 (1995): 275-80.